Unmet Supportive Care Needs of Men With Locally Advanced and Metastatic Prostate Cancer on Hormonal Treatment

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Published in:
Cancer Nursing

DOI:
10.1097/NCC.0000000000000482

Publication date:
2017

Document Version
Peer reviewed version

Unmet supportive care needs of men with locally advanced and metastatic prostate cancer on hormonal treatment: A mixed methods study

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Conflicts of Interest: The authors have no funding or conflicts of interest to disclose.

Key words: Prostate Cancer, Supportive Care Needs, Qualitative Research, Hormone Therapy

Abstract

Background: Men affected by prostate cancer undergoing hormone therapy can endure a range of symptoms that can negatively impact quality of life. Little research has been conducted to date, to understand the specific unmet supportive care needs of this patient group within the context of current service delivery.

Objective: To understand the experiences of unmet supportive care needs in men affected by prostate cancer on hormone therapy in the United Kingdom.

Intervention/Methods: Mixed methods study recruited 31 men with ≥T3 prostate cancer and treated by hormone therapy. A small cross-sectional survey (EORTC C30, PR25, Self-Management Self-Efficacy Scale and the Supportive Care Needs Survey) was used to inform the interview schedule. Semi-structured interviews were conducted and framework approach was used to analyze the data.

Results: A range of complex unmet supportive care needs were related to physical, psychological/emotional, intimacy/sexual, practical, health system/informational, existential and patient/clinician communication needs are experienced. Men articulated that current healthcare delivery is failing to provide a holistic person-centred model of care.

Conclusion: This is one of the few studies that has identified the unmet supportive care needs of men receiving hormone therapy for ≥T3 prostate cancer. The needs are multiple and far-ranging.

Implications for practice: Despite national cancer reforms, unmet supportive care needs persist. The findings from this study may be central in the re-design of future services to optimise men's quality of life and satisfaction with care. Clinicians are encouraged to use these finding to help them optimise care delivery and individual quality of life.

Introduction

Currently 250,000 men are affected by prostate cancer in the United Kingdom [1]. Data identifies that more males are diagnosed at an early stage (59% diagnosed at stage I or II) than at an advanced stage (41% diagnosed at stage III or IV). Moreover, around 1 in 5 of males will have metastases at diagnosis (stage IV) [2]. Men with locally advanced or metastatic prostate cancer where curative intent is no longer the treatment goal, face distinct challenges in contrast to men with localised prostate cancer [3]. Male hormones, specifically testosterone, fuel the growth of prostate cancer. By reducing the amount and activity of testosterone, the growth of advanced prostate cancer is slowed and controlled, but not cured. Hormone therapy is the main treatment for men with disseminated prostate cancer that is easily administered treatment, but it is not without side-effects [4].

Men undergoing hormone therapy may experience the following psychological effects: mood disturbance, cognitive impairment, difficulties with self-image and masculinities; physical effects such as hot flushes, osteoporosis, spinal cord compression, fatigue, sexual dysfunction, and changes in muscle mass, and adiposity [5] Similar to men with localised prostate cancer, men with advanced stage disease report higher levels of psychological distress, poorer quality of life and greater symptom burden [6]. There is evidence acknowledging that men affected by prostate cancer have reported a range of needs[7,8] that include: informational needs [9,10], self-management of urological symptoms [11], psychological problems [12] and sexual needs [4,13-15]. Supportive care is a person-centred approach to the provision of the necessary services for those living with or affected by cancer to meet their informational, spiritual, emotional, social, or physical needs during diagnosis, treatment, or follow-up phases including issues of health promotion and prevention, survivorship, palliation and bereavement [9,16,17].

In the UK, and internationally, the drive to find alternative methods of service delivery in this patient group are demonstrated by a range of studies [18-20]. As the prevalence of prostate cancer increases alternative models of follow-up care are now being considered [21]. Recently, a systematic review of the evidence [22] highlighted the substantial impact of cancer and treatment on long-term health and quality of life. This posed the question about the most appropriate configuration of health care services and follow-up models of care. However, patients' perspectives and their experiences of supportive care are not well articulated within the existing evidence base[23]. Previous research has mainly focused on symptom experience and quality of life using both qualitative and quantitative approaches[6,24-26] but has not specifically addressed unmet supportive care needs experienced within existing health services. Two recent systematic reviews [8,27] concluded that there is a dearth of research to help guide clinicians on the supportive care needs of men undergoing hormone therapy, and to optimise a person-centred, holistic model of shared care for these men. We need further understanding as to why unmet supportive care needs persist in current care delivery in the UK, despite national cancer reforms to improve and optimise supportive care [28] for people living with prostate cancer.

This is the first study to address, what are the experiences of unmet supportive care needs in men affected by prostate cancer on hormone treatment in current healthcare?

Study design, sample and methods

Institutional ethical approval (Caldiott/CSAppGN021211) was granted for this mixed methods study and was conducted in line with the consolidated criteria for reporting qualitative research (COREQ) [29]. Participants were recruited into the study based on the following inclusion criteria: 1) diagnosed with >T3 prostate cancer on hormone therapy, 2) adults (≥18 years), 3) deemed physically/psychologically well to participate in the study by a member of the clinical multidisciplinary team, and 4) able to understand and communicate in the English language. Exclusion criteria: 1) patients unable to meet the inclusion criteria and 2) unable to provide written informed consent. Participants were recruited from a main cancer center in Scotland, UK.

A total of thirty-five men were invited, of which thirty-one men consented to participate (88.6% response rate). Reasons for non-participation included feeling unwell as a result of treatment (n=2), and not interested (n=2). Patients (n=31) were sent a postal questionnaire by a member of their healthcare team and a stamped, addressed return envelope, to inform the development of the interview topic guide for the qualitative component of this study.

Variables

Age, socio-economic (Scottish Index of Multiple Deprivation [SIMD]), cancer stage, prostate specific antigen (PSA) and co-morbidities were collected from case records.

Supportive Care Needs Survey

The Supportive Care Needs Survey (SCNS) [30] is an instrument for assessing the perceived needs of people diagnosed with cancer. The 34 items are mapped to the following five

domains: psychological, health system, physical and daily living, patient care and support, and sexuality. Reliability and validity of this instrument has been previously demonstrated, including with men on treatment for prostate cancer [30,31].

Self-management Self-Efficacy Scale (SE Scale)

The SE Scale [32] provides an assessment of participants' belief and confidence to perform their self-management. Self-efficacy is a general term used to describe the belief that one can perform a novel or a difficult task, or cope with adversity in various domains of human functioning. Reliability and validity of the general self-efficacy scale has been demonstrated previously [32]. No normative data exists for this questionnaire.

EORTC Quality of Life (QLQ C30) Prostate module (PR25)

The QLQ C30 [33] and the PR25 [34] comprise an integrated measurement system for HRQoL in cancer participants. Reliability and validity of the QLQ C30 [33] and the PR25 [34] have been demonstrated previously**.** Normative data is available for the QLQ C30 detailed in Table 1 for a heterogeneous sample (all prostate cancer stages), but no normative data is available for the PR25.

Interview Design

Data were collected between January and May 2015. Exploratory semi-structured interviews were conducted using a topic guide informed by existing literature, the original research question, the questionnaire data from the 31 respondents and the classification of supportive care needs [8,9,16,17] (Table 2). Purposive sampling of the interviews (n=8) ensured maximum variation by: patients' age (67-84 range), socio-economic background (SIMD 1-5), time since diagnosis (April 2013 – November 2014) and prevalence of the number of existing co-morbidities (0-5 range). The study sample was designed to enable the researchers to explore

some diversity in men's experiences of follow-up care. The study's multidisciplinary team included a Senior Prostate Cancer Specialist Nurse (CP) and a Professor of Surgical Uro-Oncology/Consultant Urological Surgeon with special interest in prostate cancer (GN) who commented on emergent themes and areas that might be worthy to probe in subsequent interviews. The common themes were continually reviewed. Field notes were written immediately following the interviews to record any unrecorded conversations before and after the "formal" interview.

Description of Interview

All interviews were conducted in the participants' homes by CP, who was responsible for the overall research process. Interviews were digitally recorded with the patient's written consent. The interviews began with an open-ended, non-directive question to encourage the men to speak about their experiences of their follow-up care. Open-ended probe questions were also used to elicit greater detail of experiences shared by participants (Table 3).

Analysis of qualitative and quantitative data

The in-depth, semi-structured interviews lasted 40-90 minutes. Recordings were transcribed verbatim, cross-checked for accuracy and identifying information removed. CP coded all of the interviews and coding was subsequently verified by GN, ensuring a close match. Framework Analysis [35] was used to examine commonalities and differences within and between the transcripts. Broad themes were identified first and then broken down in to sub-themes. An electronic matrix display (in Microsoft Excel) was used to keep a transparent account of how themes were derived and this display included original links to the data. Triangulation strategies included comparison of the study results with those in previous studies conducted in the patient population [9,12,35] and with the data collected from the

questionnaire survey (n=31). The questionnaire data were analyzed using traditional exploratory analysis and descriptive statistics [36] in SPSS version 21.

Results

Thirty-one men participated in the cross-sectional survey (Table 4) and eight men took part in the in-depth interviews (Table 5). The mean age of the study participants was 80.1 years (SD 6.9). Men reported lower levels of self-efficacy 3.3, (SD .9) when compared to other published data [37] that may have influenced the experience of unmet supportive care needs in this patient population. Questionnaire data identified that men reported a range of symptoms (urinary, fatigue, pain, and bowel), reduced quality of life (Table 4). When compared to normative data (Table 1) the current study population reported lower functional outcomes that included: physical function, role function, cognitive function, but higher emotional and cognitive function. Men reported higher levels of diarrhoea, but less symptomology on all other scales when compared to normative data. Despite being a relatively small sample of men (n=31) men reported a range of unmet supportive care needs related to the fear of cancer spreading (n=13, 41.9%), lack of energy/tiredness (n=10, 32.3%), worry that the results of treatment are beyond your control (n=9, 29%), uncertainty of the future (n=9, 29%), and being given inadequate information (n=9, 29%) see Table 6. Interestingly, men further articulated these specific unmet needs and shared their experiences in greater depth in the qualitative findings.

Psychological/Emotional Consequence

Men spoke about uncertainty, worry and emotional needs of living with advanced prostate cancer and the impact at diagnosis:

"he *[consultant] said well I have got your results and they are bad news, they have spread. Gasp, then I take a deep breath, and I asked where it has [cancer] spread to? The reply was everywhere. I mean what does that mean, I was left in complete shock. No support, no nurse to speak to help me understand what everywhere meant, so I thought I only have a few weeks to live before I die"* (#3, 77 years).

Men emphasised the need for emotional support at hospital appointments:

"*… you know you get yourself all in a stutter, and what you have been told, you forget as you only focus on what is ahead of you … you need somebody with you, you need two [people], or a nurse to take you through what the doctor has just told you*" (#2, 76 years).

This was a similar experience to another man:

"*I thought they were going to do something with the catheter, I didn't realize I was getting the results, so of course I got the results on my own, didn't take everything in, well obviously somebody has just confirmed to you that you have got terminal cancer it's a bit of you know, a kick in the stomach, my wife should have been with me*" (#5, 67 years).

Another man expressed his need to see a nurse for additional support:

"*I was not offered to speak things over with the nurse, to soften the blow so to speak, or to understand what I was just told*" (#3, 76 years).

Physical symptoms

The majority of men described symptom experiences of weight gain, hot flushes, fatigue and weakness. This had a minor consequence on their quality of life, and was accepted as part of living with cancer and treatment. However, some men expressed a negative impact of their

symptoms on daily life as a result of pain and urinary symptoms and according to one participant:

"*I can only sleep about 2 or 3 hours at a time …and I am back up for the loo [void] all night. It's this arm, and then this hip, em and sometimes this shoulder that is sore during the night*" (#8, 74 years).

Another man spoke about his initial experience of bone pain:

"*the pain was terrific in my back, and then I had to go onto the patches, but it is controlled now. I needed to keep asking my GP for help, I couldn't even get out of my bed, and it was a problem as how could I even get to the toilet? I mean I felt helpless with this pain, and affected my wife too seeing me like this*" (#7, 84 years).

Men spoke about the functional issues of their symptom burden:

"*if I want to go out, the biggest problem is that with the water works … when I need shopping I need to wait until the afternoon to do that, as there are no toilets nowadays, half of them are shut. So your confidence is affected, as if you are desperate when you need to go, you need to go"* (#6, 79 years).

Interpersonal/Intimacy

Some men experienced unmet sexual needs but for other men they felt that they were too old to think about or bother with sex. Older participants appeared to accept that treatment had brought their sex lives to a halt permanently, and were unlikely to pursue further treatment to restore or improve their sexual function:

"*I have no libido, I am too old I think, I am 79. Interviewer: does that bother you or is it a concern to you? No not all, I would not say that my wife is all of that keen [laughing], she is late 70 as well, and so it doesn't bother us. I think she is happier [laughing]*" (#6, 79 years).

Age, however, was not always correlated to the experience of unmet sexual needs as identified from this 82 year old man:

"*She is [wife] actually quite wonderful and must be very frustrating for her living with me, my sex life has just disappeared, but I think they are going to give me a pill. I no longer have the urge but my wife is 15 years younger than me, so I need to make her happy, that I am still a man*" (#1, 82 years).

Another man spoke about the impact of his reduced sexual function on his quality of life:
"*to be honest with getting older I have less urges to chase women around, and he (consultant) says that will happen with this treatment, you just lose the urge for a bit of dalliance. Interviewer: Does this impact upon your quality of life? Well, yes it does particularly whilst on holidays and wanting a good time if you know what I mean*" (#5, 67 years).

Some men also had limited understanding about the options available for their erectile dysfunction, and some expressed worries that intervention would worsen their prognosis:
"*There is none, and getting an erection is [an] impossibility, after the first injection there was a limited activity, but the second one, then nope, nothing. Interviewer: Can you tell me more about that? Well actually, what I thought was and what I was frightened of, was that if I*

improved that aspect of things, it was impinge on the other [prostate cancer treatment]" (#3, 77 years).

Men also spoke about changes in their masculinity and body image:

" *… It like the testes, I mean do they go smaller? Interviewer: Have you noticed this? oh yes, the testes are definitely down, shrunken wee [little] things now. I don't know why they just don't take them out*" (#6, 79 years).

Practicality of Living with Prostate Cancer and Treatment

A common need across the men was difficulties in attending out-patient clinics due to reduced mobility and difficulties with hospital transportation.

"It is a struggle … I have got a niece and she is affa [awful] obliging, she took me, and then my neighbour took me, because we have got a car that I am not able to drive anymore, it is sitting in the garage, and it was a new car. I was advised not to drive anymore because the bones are so, in case I have to break suddenly with my bones being so weak. I do miss the car. It was a long day with patient transport, and I was up to ninety-nine [very anxious], with nobody *to take me there, and no lunch, my wife could not come in the patient transport either with the insurance or something"* (#7, 84 years).

Other practical needs men spoke about were in relation to getting holiday insurance [travel insurance for going on vacation] as consequence of having prostate cancer:

"I want to get away on holiday again, you know, but I find it hard to get insurance that is the trouble. Interviewer: Can you tell me more about what makes it challenging? Age is for a start, and then you say I have got prostate cancer, and then they say oh, I can't cover you for that, or it will cost you £3000 quid [pounds] you know … it is a substantial amount of money, and I think that they just didn't want to cover me, you know, at that price" (#8, 74 years).

Existential Concerns

Men spoke about their concerns of their prognosis and a lack of information about what happens next in their care.

"*Nobody has told me prognosis or anything, you know, because what got me was that they told me it was stage four, and it was aggressive, how long have I got you know? Nobody told me or what is going to happen next"* (#5, 67 years).

Another man shared his experience of his need to see his GP immediately following his hospital appointment due to fears of death and dying:

"*I went immediately to my doctor [General Practitioner] at home and we were able to talk through things, and you know, I asked him the question, how long have I got, because that was my immediate reaction, because according to my consultant it was everywhere! Everywhere …uch [sigh] you know when I was going home in the car I started to think right … we have got 2 cars, well what we will do, is keep one car and get rid of the other car and put the car in my wife's name, and sort out my money in my account, we will pay that and this, and you know that is what I felt at the time"* (#3, 77 years).

Another man also expressed existential concerns:

"It was a shock, I don't know how long you have prostate cancer for before it affects you and you die? I never thought about dying before, even though when you were getting into your

eighties, you know, you push it towards the back of your mind. But eh, now I have to bring it forward and life goes on whether you are there or not" (#6, 79 years).

Lack of Health System/Information

Many of the men reported a lack of understanding and information about prostate cancer, diagnosis and treatment. Men were given various levels of written information in some basic leaflets and others were provided with more comprehensive information booklets. There is a need to tailor information to each individual man, as according to one man:

"oh it was a lot of information right enough, I initially knew what was going on, but em, now I don't know what is going on; it was too much information" (#7, 84 years).

Men also spoke about a lack of information about the potential of side-effects from their healthcare team:

"Well when I got the hot flushes, and then everything shrivelled [testes] up I wasn't given any information, but then I went up to them [healthcare professionals] they said that this is expected, but I didn't know this at the time" (#6, 79 years).

Men also spoke about the need for on-going information support: *"I got that booklet and after you get it you start reading, you know, and you understand a wee (little) bit more, and then you have got questions to ask. I did phone my consultant because I felt as if I was being left kind of high and dry"* (#7, 84 years).

Many of the participants did ask specific questions of the interviewer, such as:

"Why do I get the blood test done, what is it called [PSA] checked? … I never know what the result is, that is never discussed, I don't know any figures or that. Interviewer: Would you want to know? Oh yes I would" (#5, 67 years).

Men also spoke about difficulties in understanding the information discussed with members of their care team during clinical consultations:

"the way they talk and the way we talk is two different ways. *Speaking in a jargon that a run of the mill person does not understand"* (#2, 76 years).

Improvement in Clinician/Patient Communication

For some men they felt the quality of the communication with their care team, and conveying empathy needed improvement to optimize supportive care:

"all that I would say is when bad news is being given, it is so important to have a compassionate consultant to impart that information, but also back up nurses who can take them away from there to understand the information, and take them somewhere quiet to talk them through em, because very often when you get that news you can't hear everything, all that you hear is that you have cancer and its spread, and it's here, there and there, and wherever. You don't hear anything else, and having a nurse specially trained and has empathy, I would definitely suggest that is something to look at. I think for other people it has to be addressed, no empathy" (#3, 77 years).

Other men spoke about a lack of holistic supportive care during their clinical consultation: *"I already get that blood sample, and they check it and he tells me if it is up or down, last time he said it was up a bit, I don't know what up is, but something, and basically that is it. Interviewer: How long do you see your consultant for? Oh about 10 minutes at the most, it takes me longer to walk in and out to get the taxi, rather than the time I am in there.*

Interviewer: What else do they discuss, can you tell me more? They honestly don't really discuss anything more; he checks the blood and then see you in 3 months or so" (#4, 81 years).

Improvements in Service Delivery

The research team asked the men about their current experience of care and suggestions for improvement. For the most part men were satisfied overall with their care, but there were a number of suggestions in relation to: a) ensuring that the clinical team has empathy and compassion, b) tailored informational support including self-management advice that is easy to understand, c) having greater access to cancer nursing specialists: *"Well I don't know if you have a specialist nurse to inform and keep in touch with you, even just a quick phone call to ask how are you, if you don't need and you are fine, but at least to have the option. I think that would be good and you know you are not on your own"* (#5, 67 years), d) ensuring accurate communication between primary and secondary care: *"I really just want to make sure that my GP is told everything that is going on"* (#8, 74 years), and e) offering holistic person-centered supportive care as identified across a number of sub-themes: physical needs, psychological/emotional needs, intimacy/sexual needs, practice needs, health system/informational needs, existential needs, patient/clinician communication.

Discussion

This mixed methods study aimed to understand the diverse supportive care needs of men diagnosed with prostate cancer and treated with hormone therapy within the context of current service delivery. This study is timely to understand any existing unmet needs of people affected by cancer given our national and international cancer reforms. The findings identified that men experienced a range of unmet supportive care needs and reduced scores of

self-management self-efficacy [37]. These findings may serve to target translational research in the future, with clear implications for clinical practice. Men affected by prostate cancer on hormone therapy have areas of high unmet needs, and this was particularly relevant to men's psychological and existential needs around the time of diagnosis and into treatment. Men spoke about uncertainty for the future, feelings of death and dying, and fear of the cancer spreading, which is a consistent experience of living with cancer as a chronic illness [38]. Importantly, the findings from this study have identified that the current care delivery is failing to provide a holistic person-centered model of supportive care, with some men articulating a lack of empathy, compassion and access to specialist cancer nurses, and these findings are in keeping with existing evidence [8,15] . Moreover, men reported a range of unmet needs in relation to physical, intimacy/sexual, practical, health system/informational needs, existential concerns, emotional and psychological needs, and patient/clinician communication[8,10,39].

This study makes an important contribution to the understanding of the role of supportive care in optimizing quality of life, reducing distress and improving overall satisfaction with the care. Men articulated the need for future delivery of care to have involvement and access to cancer specialist nurses to address areas of unmet needs, a need also identified elsewhere [40]. Nurse-led care and co-ordination roles have been promoted as an important component of cancer services [41] and nurses are already providing follow-up clinics for patients with prostate cancer as part of the multi-disciplinary approach as suggested in clinical guidelines [21] to provide continuity of care for patients and their family, provide information, education and support, be accessible to patients and their family and to release consultant time [42,43].

This study provides comprehensive data to understand the complex patient-specific multi-faceted unmet needs that are experienced in current care provision in this particular patient

group. These findings are an essential precursor to inform the appropriate configuration of future service delivery. It is commonly asserted that the patients' perspective should inform clinical decision-making and direct collection of outcome data from the patient should be incorporated in clinical practice [44-47]. Patient-reported outcome measures (PROMs) are described as standardized, validated questionnaires that are completed by patients to measure their perceptions of their needs, quality of life and symptom burden [44]. Emergent evidence supports the routine use of PROMs to help to drive changes in how healthcare is organized and delivered, but also at the "individual patient perspective" to empower men to share and identify areas of unmet needs during clinical consultation. Enabling healthcare providers, such as cancer specialist nurses with the necessary education and training, could help provide person-centered interventions that enable a "participatory person-centred model of care" in a timely and effective manner [48]. Moreover, a recent systematic review [8] has identified that the Supportive Care Needs Survey [30,31] would be suitable for use in routine clinical practice as this instrument identifies unmet supportive care needs, and has demonstrated reliability and validity in men affected by prostate cancer.

Limitations

The qualitative methods were particularly useful in identifying the limitations within the current follow-up services, as described by patients in a main cancer center in Scotland. By purposive sampling of patients who had experienced varying times since diagnosis, age, socio-economic status, number of existing co-morbidities, we were able to explore some diversity in men's experiences which was strength to the study. There were a few shortcomings however, and one of which is the cross-sectional design; hence our knowledge is limited to a "snap-shot". As the population of men affected by prostate cancer increases,

and the need for monitoring and management, we need to understand how supportive care needs change over time, to enable healthcare professionals to target effective and appropriate intervention in a timely manner. A further limitation is that of retrospective memory recall bias in the assessment of supportive care needs. Retrospective questionnaires and interview techniques are prone to errors and biases as a result of autobiographical memory, as this places demands on participants to accurately recall their experiences (that is to say, for example, over the past month) [49,50]. Consequently, the "real life" validity of the data is unknown. However, this study is one of the first to detail the unmet supportive care needs as voiced by men affected by locally advanced or metastatic prostate cancer treated with hormone therapy in the UK.

Conclusion

The study identified that men with prostate cancer treated with hormone therapy experienced a range of complex unmet supportive care needs. Our findings can inform translational research that aims to deliver a multimodal supportive care intervention tailored at the "individual level of need". However, in the meantime, healthcare professionals are encouraged to reflect upon these findings to ensure a holistic and person centred care delivery, for each and individual man.

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Table 1 Normative data for the EORTC C30

Constructed scales	Mean	(SD)	Median	IQR
Global health status/quality of life				
Global health status/QOL	68.4	(22.2)	66.7	[50-83.3]
Functional scales				
Physical functioning	80.2	(25.6)	93.3	[66.7-100]
Role functioning	82.7	(28.2)	100	[66.7-100]
Emotional functioning	76.6	(23)	83.3	[66.7-100]
Cognitive functioning	83.2	(20.8)	83.3	[66.7-100]
Social functioning	80.2	(27.2)	100	[66.7-100]
Symptom scales / items				
Fatigue	26.9	(26.6)	22.2	[0-44.4]
Nausea and vomiting	5.1	(14.2)	0	[0-0]
Pain	23.3	(30.3)	0	[0-33.3]
Dyspnoea	16.8	(25.7)	0	[0-33.3]
Insomnia	24.5	(30.5)	0	[0-33.3]
Appetite loss	10.4	(23.6)	0	[0-0]
Constipation	14.6	(27.2)	0	[0-33.3]
Diarrhoea	8.4	(19.4)	0	[0-0]
Financial difficulties	9.0	(21.5)	0	[0-0]

Table 2. Classification of the 11 Domains of Supportive Care Needs

Domain of Need	Definition
Physical Needs	Experience of physical symptoms such as fatigue, urinary symptoms, bowel symptoms, pain, hot flushes, etc.
Psychological/emotional needs	Experience of psychological/emotional symptoms such as anxiety, depression, worry, despair, fear, etc.
Family-related needs	Experience of fears/concerns for the family, dysfunctional relationships, etc.
Social Needs	Experience of reduced social support, social isolation, loneliness, etc.
Interpersonal/Intimacy needs	Experience of difficulties with self-image and masculinities, reduced libido, erectile dysfunction, compromised intimacy with partner, fertility, etc
Practical Needs	Situations of transportation, out-of-hours access to healthcare, financial support, etc
Daily Living Needs	Experience of restriction in daily living tasks such as exercise, housekeeping, etc
Spiritual/Existential Needs	Existential concerns such as fear of death, death and dying, fears regarding afterlife, etc
Health System/Information	Experience of a lack of information, uncertainty of follow-up care, lack of information in relation to treatment and diagnosis, etc
Patient-Clinician Communication Needs	Quality of communication between patients and healthcare professionals, satisfaction with care, shared decision-making, etc
Cognitive Needs	Experience of cognitive impairments, memory loss, etc.

Table 3. Interview Topic Guide

- Can you tell me about the care and treatment that you have received?
- Can you tell me what you think about the care you have received from healthcare professionals (at the hospital [doctors, nurses, AHP's], in the community [GP's, community nurses, practice nurses] and out-of-hours (NHS 24)?
- Experiences of co-ordinating hormone injections, taking tablets?
- Experiences of living with the side-effects? Do you talk about the side-effects with your care team? If not, why not?
- What information have you been provided with about prostate cancer, treatment and potential side-effects?
- In general, how do you feel about the support that you have received from your healthcare providers?
- Positive experiences of follow-up care?
- What happens at your hospital appointments? What are you asked about? PSA results? How frequently? Who gives your injections? Takes your bloods? Who gives you the results?
- Are there any improvements that might be made that could have enhanced the care that you received?
- What could have been done better for you?

Table 4 Participant Characteristics of the Small Cross-Sectional Survey

Variables		***N (%)***	
SIMD*		*n=5 (16.1%)*	
1		*n=2 (6.5%)*	
	2	*n=4 (12.9%)*	
	3	*n=12 (38.7%)*	
	4	*n=8 (25.8%)*	
	5		
Clinical Stage:			
	cT3NxN0	*n=4 (12.9%)*	
	cT3NxN1b	*n=17 (54.8%)*	
	cT4NxN1b	*n=10 (32.3%)*	
		Mean	**SD**
Age		*80.1*	6.9
PSA (most recent)		*26.9*	51.6
Number of co-morbidities		*2.1*	1.6
Date of diagnosis (years)		*1.7*	.9
EORTC C30			
Quality of Life		*69.6*	23.9
Physical Function		*78.0*	25.1
Role Function		*66.7*	24.2
Cognitive Function		*66.7*	22.3
Emotional Function		*88.2*	16.9
Social Functioning		*85.3*	16.5
Fatigue		*26.1*	20.0
Nausea and Vomiting		*1.9*	8.1
Pain		*11.8*	19.3
Dyspnoea		*11.8*	23.4
Insomnia		*17.6*	29.1
Appetite Loss		*5.8*	13.1
Constipation		*5.9*	13.1
Diarrhoea		*17.6*	23.9
Financial		*3.9*	11.1
EORTC PR25			
Urinary Symptoms		*24.3*	20.6
Bowel Symptoms		*6.4*	8.6
Hormone Related Symptoms		*12.7*	9.8
Sexual Activity		*15.7*	24.6
Self-Management Self-Efficacy		*3.3*	.9

N=17, **high score for a functional scale** represents a *high / healthy level of functioning*, a **high score for the global health status / QoL** represents a *high QoL*, but a **high score for a symptom scale / item** represents a *high level of symptomatology / problems (0-100)** (1 most deprived, 5 Least deprived)

Table 5 Participant characteristics of the semi-structured interviews

Name	Age	Diagnosed	Clinical Stage	Co-morbidities	PSA (Recent)	SIMD (1 most deprived, 5 Least deprived)
#1	82	August 2014	cT3NxM1b	Type 2 diabetes, progressive CKD 4, Hypertension	10.7 ug/L	2
#2	76	August 2014	cT3NxM1b	CKD stage 3, IHD, Type 2 diabetes, hypertension, AF	10.7 ug/L	4
#3	77	September 2014	cT3NxM1b		22.4 ug/L	3
#4	81	October 2013	cT3NxM1b	OA knees	77.0 ug/L	4
#5	67	January 2014	cT3NxM0		45.4 ug/L	2
#6	79	November 2014	cT3NxM1b		76.9 ug/L	4
#7	84	November 2014	cT4 cNXN1b	Hypertension, IHD, Depression	7.8 ug/L	1
#8	74	April 2013	cT3NxM1b		1.6 ug/L	5

Table 6 Distributions of Unmet Supportive Care Needs

Unmet Need*	This was not a problem for me as a result of cancer. N (%)	I did need help with this, but my need for help was satisfied at the time N (%)	Low unmet need. I had little need for additional help. N (%)	Moderate unmet need. I had some need for additional help. N (%)	High unmet need. I had strong need for additional help. N (%)
Pain	20 (64.5%)	6 (19.4%)	2 (6.5%)	2 (6.5%)	1 (3.2%)
Lack of energy/tiredness	12 (38.7%)	9 (29%)	6 (19.4%)	2 (6.5%)	2 (6.5%)
Feeling unwell a lot of the time	20 (64.5%)	8 (25.8%)	2 (6.5%)	0 (%)	1 (3.2%)
Work around home	25 (80.6%)	4 (12.9%)	1 (3.2%)	0 (%)	1 (3.2%)
Not being able to do the things that you used to do	15 (48.4%)	10 (32.3%)	3 (9.7%)	1 (3.2%)	2 (6.5%)
Anxiety	22 (71.0%)	3 (9.7%)	4 (12.9%)	1 (3.2%)	1 (3.2%)
Feeling down or depressed	19 (61.3%)	5 (16.1%)	5 (16.1%)	1 (3.2.%)	1 (3.2%)
Feelings of sadness	20 (64.5%)	6 (19.4%)	4 (12.9%)	1 (3.2%)	0 (%)
Fear about the cancer spreading	11 (35.5%)	7 (22.6%)	8 (25.8%)	3 (9.7%)	2 (6.5.%)
Worry that the results of treatment are beyond your control	17 (54.8%)	5 (16.1%)	6 (19.4%)	2 (6.5%)	1 (3.2%)
Uncertainty about the future	15 (48.4%)	7 (22.6%)	8 (25.8%)	0 (%)	1 (3.2%)
Learning to feel in control of your situation	18 (58.1%)	6 (19.4%)	5 (16.1%)	0 (%)	2 (6.5%)
Keeping a positive outlook	16 (51.6%)	12 (38.7%)	2 (6.5%)	1 (3.2.%)	0 (%)
Feelings about death and dying	14 (45.2%)	10 (32.3%)	5 (16.1%)	1 (3.2%)	0 (%)
Changes in sexual feelings	17 (54.8%)	7 (22.6%)	5 (16.1%)	1 (3.2%)	1 (3.2%)
Changes in sexual relationships	17 (54.8%)	7 (22.6%)	4 (12.9%)	2 (6.5%)	1 (3.2%)
Concerns about the worries of those close to you*	15 (48.4%)	7 (22.6%)	4 (12.9%)	3 (9.7%)	1 (3.2%)
More choice about which cancer specialist to see	13 (41.9%)	10 (32.3%)	5 (16.1%)	2 (6.5%)	1 (3.2%)
More choice about which hospital you attend	18 (58.1%)	13 (41.9%)	0 (%)	0 (%)	0 (%)
Reassurance by medical staff that the way you feel is normal	18 (5.1%)	9 (29.0%)	2 (6.5%)	2 (6.5%)	0 (0%)
Hospital staff attending promptly to your physical needs	17 (54.8%)	12 (38.7%)	0 (0%)	2 (6.5%)	0 (%)
Hospital staff acknowledging, and showing sensitivities to your emotional needs	17 (54.8%)	12 (38.7%)	0 (%)	2 (6.5%)	0 (%)
Being given written information about the important aspects of your care	13 (41.9%)	11 (35.5%)	5 (16.1%)	1 (3.2%)	1 (3.2%)
Being given information (written diagrams, drawings) about managing your illness and side-effects at home	15 (48.4%)	7 (22.6%)	7 (22.6%)	1 (3.2%)	1 (3.2.%)
Being given explanations for those test for which you would like explanations	15 (48.4%)	9 (29.0%)	5 (16.1%)	1 (3.2%)	1 (3.2%)
Being adequately informed about the benefits	15 (48.4%)	9 (29.0%)	5 (16.1%)	1 (3.2%)	1 (3.2%)

and side-effects of treatment before you choice to have them					
Being informed about test results as soon as feasible	13 (41.9%)	10 (32.3%)	3 (9.7%)	4 (12.9%)	1 (3.2%)
Being informed about cancer that is under control or diminishing	15 (48.4%)	9 (29.0%)	5 (16.1%)	2 (6.5%)	0 (%)
Being informed about the things that you can do to get well	16 (51.6%)	9 (29.0%)	4 (12.9%)	2 (6.5%)	0 (%)
Having access to professional counselling	18 (58.1%)	8 (25.8%)	3 (9.7%)	1 (3.2%)	1 (3.2%)
Being given information about sexual relationships	25 (80.6%)	3 (9.7%)	3 (9.7%)	0 (%)	0 (%)
Being treated like a person not just another case	14 (45.2%)	13 (41.9%)	3 (9.7%)	1 (3.2%)	0 (%)
Being treated in a hospital or clinic that is physically pleasant as possible	14 (45.2%)	14 (45.2%)	1 (3.2%)	2 (6.5%)	0 (%)
Having one member of hospital staff with whom you can talk to	14 (45.2%)	10 (32.3%)	5 (16.1%)	1 (3.2%)	1 (3.2%)